SUMMARY

This innovation project started with a request from a local prosthetic rehabilitation team to update their treatment programme with new scientific insights. This request was primarily based on their concern that skills learned by patients in the clinical setting were not preserved after discharge from the rehabilitation centre. This seemingly simple request resulted into a complex enquiry. The key question here is: “how to link new scientific insights with rehabilitation practice, in this case a prosthetic rehabilitation setting?” More specifically: what scientific insights are in potential relevant for such a setting, how to translate these insights in useful tools for rehabilitation professionals, how to assist professionals in putting them into action, and indeed what kind of research methodology is therefore useful? These were the questions that came to the fore. Many knowledge translation projects have tried to bring research knowledge into action, and faced several difficulties along the way. These difficulties are often presented in the metaphor of ‘the research-practice gap’. The difficulties experienced make that researchers and professionals point towards each other for not being able or willing to overcome this gap.

In this thesis we explored alternative solutions directions in linking science and rehabilitation. This thesis draws on a sociologically informed conception of science that considers both clinical and scientific knowledge, as different knowledge practices that are of equal value for improvement of local settings. Other sources of inspiration were change management principles and practices, participatory action research, theory-driven programme evaluation and integrated knowledge-to-action translation research. So this thesis can be read on two levels: (1) on a practical level, addressing the question “How to improve a prosthetic rehabilitation programme with scientific knowledge from ‘within’ a local setting?” and (2) on a research level, addressing the question “What are the implications of a more sociological way of thinking and doing innovation and implementation research?”

After the introduction, in Chapter 2, the first steps in this innovation project are described. Participatory research methodology helped us to specify the problem felt by the prosthetic rehabilitation team: they feared a decline in outcome of patients with lower limb amputation (LLA) after discharge from the rehabilitation centre. Triangulation of data derived from analysis of treatment documents, individual and focus group interviews with professionals and patients, and treatment observations, revealed a critical issue. The carry-over problem had to do with the struggle of professionals to encourage patients to be active learners, which in turn appeared to be related to the biomedically and biomechanically underpinned treatment programme. Learning theories that encourage patients to actively participate in their training were barely integrated in the treatment programme.
Summary

A literature study revealed the value of self-management education for patients with chronic diseases and that of task- and context-specific training for patients with neurological conditions. Both approaches appealed on the problem-solving capacities of patients; the first to provide patients with the psychological skills to deal with the consequences of the condition (self-management education) and the second to teach them motor skills (task- and context-specific training). Therefore their theoretical principles were transferred and translated to the prosthetic rehabilitation programme, and related practices specified with amputation-specific information gathered by focus group interviews with professionals and patients. This resulted in two concept modules: a psycho educative training in which patients actively learn to cope with post-discharge problems, and a circuit training, in which patients actively learn to deal with their prosthesis. The participatory collaboration between the professionals and the research team made that all stakeholders were sincere and driven to work on the implementation of the newly developed treatment programme.

To examine if we could objectify the feared decline in outcome of patients with LLA after discharge from prosthetic rehabilitation, we conducted as a second step a concurrent mixed methods study, described in Chapter 3. More specifically, research knowledge on the functional performance, participation and autonomy of 13 patients with LLA, and the barriers and facilitators affecting these outcomes, was collected at discharge of the rehabilitation centre (T0) and 3 (T1) and 6 months (T2) later. Functional performance was measured using the Two-Minute Walk Test and L test, and participation and autonomy using the Impact on Participation and Autonomy questionnaire. Barriers and facilitators were identified in semi-structured interviews. After discharge, 9 of 13 patients declined in functional performance. Main limitations in participation and autonomy were observed in the “family role” and “autonomy outdoors” domains, with scores of fair to poor. Many diverse factors were found to affect functional performance and participation after discharge, acting sometimes as barrier for some individuals and as facilitators for others. Changes in outcomes on functional performance were not always in line with those observed in participation and autonomy. The presence of barriers and facilitators also fluctuated over time and no collective time patterns were found. We concluded that patients should be educated about the distinctive fluctuations after discharge and the barriers and facilitators in the environmental, personal and medical contexts they could encounter post-discharge. Considering the great diversity in individual reactions to perceived barriers we suggested to teach patients a generic approach to dealing with problematic situations, as seen in self-management education.

To be able to integrate self-management into prosthetic rehabilitation we gained more insight into the differences and similarities between physical rehabilitation medicine (PRM) and self-management education (SME). Chapter 4 describes a comparative text analysis to trace the
differences between and similarities in these knowledge practices. Inspired by discourse analysis, texts on both approaches were contrasted as having vocabularies of their own, expressed under certain material conditions. Four issues arose. First, the difference in illness trajectories between a sudden transition from an able to disabled person after a disease with acute onset in PRM and the indefinite and unpredictable course of a chronic disease in SME. Second, the different material and social set-up of clinical practice delivered by a multidisciplinary team in rehabilitation centres and self-management education originally delivered by peers in local community settings. Third, the influence of these different implementation environments on goal-setting, that is the use of treatment goals within rehabilitation practices versus life goals within self-management education. And fourth, the relative neglect of social theory in PRM compared to SME. This analysis provided us with knowledge on how to give SME a considered place in rehabilitation. Rehabilitation practice could for example change the focus from treatment to life-goals during the rehabilitation process, integrate training of problem-solving skills in real life settings, use the expertise of peers, and teach patients when to grasp the baton of responsibility and when to hand it over to others.

Chapter 5 describes a integrated knowledge-to-action (KTA) project in which the knowledge gathered with participatory action research, mixed methods research, and discourse analysis was brought together, in order to specify and implement the self-management intervention in prosthetic rehabilitation. The scope of this chapter is limited to the development and implementation of the motor learning module of the self-management intervention: the circuit training. Our sociologically informed conception of science influenced the activities chosen in the phases of the KTA framework. The knowledge creation process resulted in a detailed description of the principles and practices described in scientific literature on self-management education and task-and context-specific training. Adapting the knowledge to the local context consisted of two phases: tailoring of principles and practices to the target group (ie, patients with LLA) with help of the professionals’ knowledge, and a more generic translation of the principles and practices into concrete treatment instructions, for example on how to give content to variation, or incorporate techniques for enhancing self-efficacy and challenge problem-solving of patients with instructions and feedback. Possible barriers to knowledge use were identified on 3 levels: the organizational, professional and target group level. To tackle these barriers several activities were selected, tailored and carried out in close collaboration with professionals, staff and delegates of a national association for patients with an amputation. During a pilot implementation of the intervention, we gained insight on how professionals brought the knowledge into practice and which adaptations were needed. In a focus group with the professionals and manager, the intervention and the KTA process were evaluated. Patients reflected on the training in individual
interviews. In this iterative and interactive process the intervention was continuously refined and evaluated in practice, which led to a training that was optimized for the local context. The genuine partnership between the professionals and researchers led to a shared ownership of the intervention.

Chapter 6 discusses an overall theme that came to the fore during this innovation project, namely the complexity inherent in establishing evidence-based practice (EBP) in a prosthetic rehabilitation team. We illustrated this with help of the case of prosthetic prescription for elderly patients with a transfemoral amputation due to dysvascular disorders. The discussion draws on empirical material from individual and focus-group interviews with members of the prosthetic team, information on technological advancements presented on websites of the orthopaedic industry, guidelines and scientific literature on prosthetic rehabilitation and literature on the research-practice gap. The discussion indicated that a prosthetic rehabilitation team needs to deal with lack of evidence, contradictory results, various classification systems, diverging interests of different stakeholders and many modifying factors, and all of this in a continuous technological changing environment. To reduce the complexity in working in a evidence based manner we suggested that researchers should integrate research designs with different strengths but not sharing the same biases. That may help in conducting relevant research with this diagnose group in which multimorbidity and multifaceted disability are common. Also articulating clinical knowledge, patients’ needs and values in a systematic way, helps in providing depth, nuance and context for evidence based practice issues in prosthetic rehabilitation. We emphasized that it is a shared responsibility of professionals and researchers to deal with the complexity of EBP in prosthetic rehabilitation. We therefore suggested to replace based in EBP for informed. In evidence informed practice (EIP) professionals are encouraged to be knowledgeable about findings coming from all types of scientific studies and researchers are urged to help translate these findings in an integrative manner.

In the general discussion in Chapter 7 we reflect upon the way we conducted our innovation research in a sociologically informed manner, and the lessons we learned along the way. First, it is discussed how the role of theory in innovation and implementation research is a complex one. It is explicated that there are different kinds of theories: biomedical and psychosocial theories that inform the content and implementation context of rehabilitation programmes, theories on how to conduct evaluation, innovation and implementation research in rehabilitation practice, theories that help in describing knowledge and putting knowledge into action, and theories on the nature and status of scientific results. This means that innovation researchers should have conceptual analytical skills to work with these different theories on different levels, and understand the impact of the theories on the work to be done. Subsequently, the importance and
end results of engaged partnership with professionals of the multidisciplinary team and patients with LLA is discussed. The involvement of all stakeholders in a cyclic and interactive translation process meant that they could understand and build upon the knowledge practices in which they participated, which served as a catalyst for the innovation. Thereafter, it is discussed how the use of several, often combined research methods, each with its own strengths and weaknesses, was exemplary for the research in this case study. Often, we used qualitative research methodology, sometimes influenced by a phenomenological approach, or inspired by a participative approach or by discourse analysis. Placing the KTA framework alongside a more engaged procedure implied the need to (a) explore and articulate the stakeholders perspective, (b) integrate their practical and contextual knowledge into the available research knowledge, (c) co-create the intervention to be implemented and (d) integrate the adaptations made by the professionals while ensuring that the active ingredients stay the same.

Finally, we sketch how the assumptions and methodologies used in such an innovation project impact the role of the innovation researcher. Its role is characterized by flexibility, open-mindedness and curiosity, being detached and connected at the same time, and knowing how to detail and compare relevant knowledge practices with the many methodologies available. We emphasize that the methods to be used in improving rehabilitation programmes depend on problems identified, goals to be reached, the maturity and complexity of the programme, the environment in which it has to be implemented, the researchers’ and stakeholders values and the political and organizational context of the programme. The self-management intervention under study in this innovation project is tailored specifically to the local setting: situated and time-related choices were made in relation to the content of the self-management programme. Though other rehabilitation centres can profit from the knowledge, products and learning experiences that were generated in this innovation project.

This thesis made me realize that the metaphor of ‘bridging the gap between scientific research and clinical practice’ is actually no longer tenable. It became clear to me that the difficulties that are experienced in bringing research knowledge into action in rehabilitation practice is rather a knowledge production problem than a knowledge transfer problem. When innovation researchers link different kinds of knowledge (research, practical and contextual knowledge) on an analytical impartial manner, it is no longer knowledge that is transferred from the world of research to the world of rehabilitation. Indeed, these different kinds of knowledge are part of the same (rehabilitation) world, but are given content by their own material and social set-up. So, there are no two different worlds divided by a gap. Thus, let’s move beyond this old metaphor and work on linking research and rehabilitation knowledge practices in order to contribute to the improvement of both practices.